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Report of the Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members*

Note by the Secretariat

The Secretariat has the honour to transmit to the Human Rights Council the report of the Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members, Alice Cruz, prepared in accordance with Council resolution 35/9. In the report, the Special Rapporteur outlines her vision, priorities and working methods for the next three years.

* The present report was submitted after the deadline in order to reflect the most recent developments.

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I. Introduction

1. In its resolution 35/9, the Human Rights Council established the mandate of the Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members. In the resolution, the Council recognized that, in various parts of the world, persons affected by leprosy and their family members continue to face multiple forms of discrimination and widespread barriers to their participation as equal members of society, including isolation, discrimination and violations of their human rights. The adoption of the resolution was aimed at intensifying efforts to eliminate all forms of prejudice and discrimination against persons affected by leprosy and their family members and to promote policies that facilitate their inclusion and participation.

2. The resolution mandates the Special Rapporteur to report annually to the Council, starting from its thirty-eighth session. Following the adoption of the resolution, the Council appointed Alice Cruz to lead the mandate. She assumed her duties on 1 November 2017. In the present report, the Special Rapporteur introduces leprosy and details her vision, priorities and working methods for the next three years.

II. Leprosy

A. A curable disease

3. Leprosy, also known as Hansen's disease, is a chronic infectious disease caused by *Mycobacterium leprae*. Leprosy has a long incubation period and symptoms may appear between 2 and 20 years after infection. Leprosy can occur from early infancy to very old age. The disease mainly affects the skin, the peripheral nerves, the mucosal surfaces of the upper respiratory tract and the eyes.[1]

4. Contrary to the social representation of leprosy as a highly contagious disease, leprosy is not highly infectious, and most persons (around 95 per cent) who are in contact with the disease do not develop it. In fact, most people are naturally immune to leprosy. The mechanism of transmission is not yet clear. However, leprosy is most likely transmitted through droplets, from the nose and mouth, and during close and frequent contact with untreated cases.[2]

5. Leprosy is curable with a combination of drugs known as multidrug therapy. The treatment of leprosy with only one drug can lead to drug resistance. The combination of drugs depends on the classification of the disease. Rifampicin, the most important drug, is included in the treatment for both types of leprosy (paucibacillary and multibacillary). Multidrug therapy has been supplied free of charge by the World Health Organization (WHO) since 1995. Multidrug therapy was donated until 2000 by the Nippon Foundation. Since then, it has been donated by Novartis and will continue to be so until 2020. The elimination of leprosy as a public health problem (defined as a registered prevalence of less than 1 case for every 10,000 persons) was achieved globally in 2000.[3]

6. However, the global elimination of leprosy as a public health problem may hide the fact that there are still highly endemic countries, as well as highly endemic pockets within countries. The drastic decline in the prevalence of leprosy in the last three decades has not meant that leprosy has disappeared. In fact, there is still ongoing transmission.

7. Stigmatization and discrimination remain major obstacles to the elimination of leprosy, a fact that has been agreed upon by the main stakeholders. In 2010, the General Assembly adopted resolution 65/215 on the elimination of discrimination against persons affected by leprosy and their family members and took note of the principles and guidelines

[1] See www.who.int/en/news-room/fact-sheets/detail/leprosy.

[2] Ibid.

[3] Ibid.

for the elimination of discrimination against persons affected by leprosy and their family members (A/HRC/15/30, annex). In 2016, WHO adopted the Global Leprosy Strategy 2016–2020, which is based upon three strategic pillars, the third of which is on stopping discrimination and promoting inclusion.[4]

B. Gap between curing and healing

8. Despite being curable, if not detected early and treated, leprosy can cause irreversible damage to the skin, nerves, limbs and eyes, leading to disfigurement, blindness, loss of sensation, chronic wounds and neuropathic pain.[5]

9. A unique feature of the impairments[6] caused by leprosy are their preventable nature, which depends on access to early diagnosis, treatment and high-quality care. However, late diagnosis is very frequent. Moreover, the global elimination of leprosy as a public health problem has resulted in a loss of expertise in diagnosis and treatment. Finally, a high-quality treatment to address nerve damage, which is the main cause of leprosy-related impairments, is yet to be achieved.[7]

10. Leprosy is undoubtedly a neglected disease and the lack of funds for basic and clinical research explain why the main available drugs for treating leprosy reactions (which are a major cause of nerve damage and resulting impairment) are steroids and thalidomide, the latter of which carries a high risk of causing severe iatrogenic effects.[8]

11. Institutional and extra-institutional barriers to access to an early diagnosis, lack of medical expertise among health services and professionals and drugs with severe iatrogenic effects explain why so many persons affected by leprosy claim that, after completing multidrug therapy, even though they are said to be cured, they do not feel healed.[9]

12. Few other diseases show the gap between a medical cure and the phenomenological experience of healing as much as leprosy. Such a gap is deeply forged by social mediator factors and the social determinants of health and illness, among which stigmatization and discrimination play a critical role.

C. Epidemiology and human rights

13. In 2016, 214,783 new cases were reported to WHO by 145 countries. The highest absolute and relative number of cases of leprosy were reported in India, Brazil and Indonesia. There is still a worrying prevalence in 22 countries that, according to a set of indicators (which includes prevalence, the detection of new cases and the proportion of female, child and grade-2 disability[10] cases), are identified as global priority countries for leprosy control. The countries with more than 1,000 new cases in 2016 were: Bangladesh, Brazil, Democratic Republic of the Congo, Ethiopia, India, Indonesia, Madagascar,

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[4] WHO Regional Office for South-East Asia, *Global Leprosy Strategy 2016–2020. Accelerating Towards a Leprosy-free World* (New Delhi, 2016).

[5] See www.who.int/en/news-room/fact-sheets/detail/leprosy.

[6] In the present report, the Special Rapporteur uses the terms "impairment" to refer to the loss of functioning or the detriment to the health of persons affected by leprosy and "disability" to refer to the social responses of discrimination and exclusion to leprosy-related impairments. This distinction is based upon the social model of disability, which is embraced by the Special Rapporteur in her work.

[7] WHO Regional Office for South-East Asia, *Global Leprosy Strategy 2016–2020. Accelerating Towards a Leprosy-free World — Operational Manual* (New Delhi, 2016), pp. 5–6.

[8] Alice Cruz, "Leprosy as a multilayered biosocial phenomenon: the comparison of institutional responses and illness narratives of an endemic disease in Brazil and an imported disease in Portugal", *Clinics in Dermatology*, vol. 34, No. 1 (2016), pp. 16–23.

[9] Ibid.

[10] Grade-2 disability refers to visible impairment. The grading system used by the Global Leprosy Programme consists of "grade 0" meaning no impairment, "grade 1" meaning loss of sensation in the hand, eye or foot and "grade 2" meaning visible impairment.

Mozambique, Myanmar, Nepal, Nigeria and Philippines. In endemic countries, leprosy mainly affects poorer communities and regions.[11]

14. Furthermore, as the prevalence of leprosy declines, new challenges arise, such as the increase of foreign-born cases in countries in which it has already been eliminated. In 2016, 328 foreign-born cases were reported in 23 countries.[12]

15. Finally, the number of cases reported globally is not exact, as many cases go unreported due to institutional and extra-institutional barriers in accessing leprosy-related diagnosis and treatment in many parts of the world. A large number of people continue to receive treatment for leprosy and many live with impairments caused by leprosy and with disabilities caused by their social exclusion. In addition, the figure does not cover family members of the affected individuals, who are equally affected by leprosy-related stigmatization and discrimination.

16. Despite the impressive decrease in the number of cases since the introduction of multidrug therapy three decades ago (from over 5 million cases in the mid-1980s to less than 200,000 cases at the end of 2016), no major change in the trends of newly detected cases has been observed. Most recently, an increase in new cases from 210,758 in 2015 to 214,783 in 2016 has been reported.[13] This suggests a number of things:

17. First, the prevalence rate may not be reliable in fully assessing the evolution of leprosy, since before the discovery of multidrug therapy, patients had to undergo treatment for years, sometimes for life. Following the introduction of multidrug therapy, treatment time was drastically reduced. Since 2000, such a reduction in treatment has reached 12 months for multibacillary patients and 6 months for paucibacillary patients. Paucibacillary patients may not reach the annual prevalence record, leaving them uncounted. And there are gaps in the reporting of new cases, especially in low-income countries, in which conditions are favourable for higher rates of leprosy and in which well-structured health services are lacking.[14]

18. Second, the data suggest that more efforts are required to stop the transmission of leprosy. Besides the aforementioned loss of expertise, it is necessary to reframe leprosy under the current debate on the social determinants of health and inclusive development. Leprosy's transmission depends not only on biological factors, but also on social determinants, including access to sanitation, clean water and education, among others, that have not yet been responded to by public health programmes.

19. Of the 214,783 new cases reported in 2016, 12,437 presented grade-2 disability cases, namely visible impairments. As already mentioned, impairments caused by leprosy are preventable and its incidence means that delays in access to diagnosis and to a high-quality treatment have occurred, in sum to the fundamental rights of every human being to the enjoyment of the highest attainable standard of health. In such cases, States have failed to fulfil their obligations to respect, protect and fulfil such a right.

20. Some 281 of the 12,437 new cases reported in 2016 were children with impairments. The overall rate of new cases of leprosy in children represents 8.9 per cent of all new cases, a shamefully high figure. This reveals social vulnerability as a key factor in the transmission and prevalence of leprosy. Additionally, the overall underreporting on women affected by leprosy remains a cause for great concern.[15] This is indicative of the vulnerability of women and their lack of access to health services in many settings, especially in poorer communities. The epidemiology of leprosy is linked to the continuous violation of the human rights of vulnerable groups both within countries and worldwide.

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[11] WHO Regional Office for South-East Asia, *Global Leprosy Strategy 2016–2020 — Operational Manual*, p. 2.

[12] WHO, *Weekly Epidemiological Record*, No. 35 (92) (2017), pp. 501–520.

[13] Ibid.

[14] Claudio Guedes Salgado and others, "Are leprosy case numbers reliable?", *Lancet*, vol. 18, No. 2 (February 2018), pp. 135–137.

[15] WHO, *Weekly Epidemiological Record*.

III. Long path from segregation to human rights

A. Thousands of years of human rights abuses and violations

21. Leprosy has been associated with the abuse and violation of the human rights of countless women, men and children for thousands of years. Yet, its recognition as a human rights violation is a recent development.

22. Some may argue that such violations resulted from the fact that, for a long time, leprosy was an incurable, disfiguring and disabling disease that spurred an automatic response of fear and rejection.

23. However, this type of functionalist approach does not acknowledge that many societies did not consider leprosy as a transmissible disease.[16] Moreover, in the late nineteenth century, when the theory of contagion became the paradigmatic explanatory model for leprosy's transmission, it lacked any scientific evidence to back it up. And yet, persons affected by leprosy were systematically labelled as shameful and set apart. Hence, the functionalist approach always ends up by blaming the persons who are stigmatized and discriminated against, while failing to question the persons who stigmatize and discriminate.

24. Religious and ideological beliefs, cultural practices and misconceptions are the attributing factors that supported the discrimination of persons affected by leprosy in different historical periods and regions. Certain cultural norms have provided favourable conditions for leprosy to be regarded as shameful and harmful to the social order.[17]

25. Leprosy came to embody what was socially prescribed as shameful and disrupting, and was thus rendered something beyond a mere disease. It became a symbol, a powerful metaphor, for everything that should be kept apart, whether it was attributed to punishment for sinful conduct,[18] unregulated behaviour,[19] past offences[20] and socially constructed ideas of racial inferiority,[21] among others.

26. Persons affected by leprosy have historically been deprived of their civic, political, economic, social and cultural rights. Women, men and children affected by leprosy were, and continue to be in many contexts, denied not only their dignity, but also an acknowledgement of their humanity. It is not a coincidence that it is commonly said that persons affected by leprosy experience a civil death. They have been consistently subjected to: stigmatizing language; segregation; separation from their families and within the household; separation from their children; denial of care; denial of the means of subsistence; denial of a place to live; denial of education; denial of the right to own property; impediments to marry; impediments to have children; restrictions on their freedom of movement; denial of their right to participate in community, public and political life; physical and psychological abuse and violence; compulsory internment; forced sterilization; institutionalized silencing and invisibility; and removal from history.

27. The use of leprosy as a metaphor bedevils us in public and private spaces. Its stigmatizing effects restrain the social participation of not only those affected by leprosy,

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[16] Silathan Sermrittirong and Wim H. Van Brakel, "Stigma in leprosy: concepts, causes and determinants", *Leprosy Review*, vol. 85, No. 1 (2014), pp. 36–47.

[17] Mary Douglas, "Witchcraft and leprosy: two strategies of exclusion", *Man*, vol. 26 (1991), pp. 723–736.

[18] Gilbert Lewis, "A lesson from Leviticus: leprosy", *Man*, vol. 22, No. 4 (1987), pp. 593–612.

[19] Emilio M. Fernandez, *Fantasmas de la sociedad medieval: enfermedad, peste, muerte* (Valladolid, University of Valladolid, 2004).

[20] Sermrittirong and Van Brakel, "Stigma in leprosy".

[21] Ron Edmond, *Leprosy and Empire: A Medical and Cultural History* (Cambridge, Cambridge University Press, 2006); Zachary Gussow and George S. Tracy, "The use of archival materials in the analysis and interpretation of field data: a case study in the institutionalization of the myth of leprosy as 'leper'", *American Anthropologist*, vol. 73, No. 3 (1971), pp. 695–709, and "The phenomenon of leprosy stigma in the continental United States", *Leprosy Review*, vol. 63 (1972), pp. 85–93.

but also their families. Yet, it has been imagined as something that no longer exists, something of the past, something remote, something that is still and always apart.

28. It is in this context that persons affected by leprosy and their family members continue to face endless stigmatization and discrimination in their households, communities and societies and in legislative and juridical institutions.

29. The idea that the elimination of leprosy would solve the problem of stigmatization and discrimination is a narrow approach and is indicative of limited understanding, not only of stigmatization and discrimination, but also of the dynamics of history. Eliminated diseases may re-emerge and with them stigmatization and discrimination. This is seen in countries where leprosy re-emerges with foreign-born cases, and where loss of expertise results in a delay in diagnosis. Such delays strengthen the chain of transmission and the accompanying stigmatizing and discriminatory practices.

B. A very modern disease

30. It is true that leprosy is an ancient disease. Not only is its causative agent, *Mycobacterium leprae*, old, but it has not changed significantly.[22] However, this does not mean that leprosy is a disease of the past or a residue from the past.

31. Leprosy is a contemporary disease closely linked with socioeconomic, civil and political vulnerability. Despite the dramatic decline of its prevalence in the last three decades, there are still: (a) considerable and concerning rates of incidence and transmission; (b) a high proportion of late diagnosis; (c) underreporting; and (d) emerging new challenges, such as an increase in foreign-born cases in countries that no longer have the expertise to diagnose and treat leprosy, resulting in increasing transmission.

32. Moreover, much of the legislation that deals with leprosy was produced in modern times. The contemporary social representation of leprosy results from a complex intersection between traditional myths, religious beliefs and modern ideas on contagion.

33. Until the late nineteenth century, the cause of leprosy remained unknown. It was in 1873, that the Norwegian Gerard A. Hansen identified the acid-fast, rod-shaped *Mycobacterium leprae* as its etiological agent. This breakthrough allowed for the medicalization of leprosy, that is, its transformation from a moral condition into a medical one. It also marked the modern history of leprosy, which is made up of turning points that gave rise to different State and public health policies, as well as social experiences and discriminatory practices.

First period of the modern history of leprosy (1873–1948)

34. The first period of the modern history of leprosy started with Hansen's discovery, which led to a unified response to leprosy by European experts and Governments in 1879. Such a response was based on a consensus on contagion (understood as the spread of a disease through physical contact, particularly through touch) as leprosy's transmission mechanism.[23] However, there was no evidence to support such a claim, since it was not possible to grow *Mycobacterium leprae* in vivo or in vitro. Such a consensus, alongside the description of leprosy as an "imperial danger",[24] which demanded establishing sanitary borders[25] to prevent a massive invasion of leprosy[26] among the central States, opened the way for a general agreement on the need for prophylactic segregation of persons affected

[22] See https://1drv.ms/b/s!ApNa7GHD7siggvE3a-EjQN5N83XWQg; https://1drv.ms/b/s!ApNa7GHD7sighf4wL5kqb-xONmO2vg; https://1drv.ms/b/s!ApNa7GHD7siggu1iUbSjy45Oq5CoRw.

[23] *Mittheilungen und Verhandlungen der internationalem wissenschaftlichen. Lepra-Conferenz zu Berlin im October 1897* (Berlin, Verlag von August Hirschwald, 1898).

[24] Tony Gould, *A Disease Apart: Leprosy in the Modern World* (New York, St. Martin's Press, 2005).

[25] S. Shubada Pandya, "The First International Leprosy Conference, Berlin, 1897: the politics of segregation", *História, Ciências, Saúde – Manguinhos*, vol. 10, No. 1 (2003), pp. 161–177.

[26] Zeferino Falcão, *A lepra em Portugal* (Lisbon, Royal Academy of Science, 1900).

by leprosy. This gave rise to the establishment of leprosaria around the globe. 1948 signalled the year in which leprosy experts abandoned the policy of compulsory internment.[27] However, such a policy lasted in some countries until the late twentieth century. Moreover, it can still be found in some national legislations.

35. Thousands of leprosaria were established throughout the world after the late nineteenth century, many of them implementing an official State policy of compulsory internment of persons affected by leprosy, while others emerged as non-official State policy as a consequence of the social marginalization of persons affected by leprosy.[28]

36. Segregation denied the civil and political rights of persons affected by leprosy, who were separated from their families and communities, often at a very early age. The same policy was applied in 1923 to children of persons affected by leprosy.[29] Children were forcibly separated from their parents at birth and many were also secluded from their communities. The dissemination of prophylactic propaganda was also part of this policy, which aimed at alerting the public to the dangers of contact with persons affected by leprosy. In 1924, recommendations were sent to the newly created League of Nations, urging it to take leadership in regulating the circulation of persons affected by leprosy and prohibiting them from entering foreign countries.[30]

37. There was never any scientific evidence to support prophylactic segregation of persons affected by leprosy. Nevertheless, such a policy was widespread; it reinvented leprosy in modern times as a "dreadful" disease, disseminating stigma in many parts of the world. Much of the current discriminatory national legislation was produced during this period.

Second period of the modern history of leprosy (1948–1981)

38. The second period of the modern history of leprosy began with the discovery, in 1943, by the North American Guy Faget of a drug with some reasonable degree of efficacy in curing leprosy, despite its long-term use and severe iatrogenic effects.[31] The efficacy of dapsone in curing leprosy led to a transition from a policy of compulsory segregation to a policy of decentralization to general health services. It was in this period that WHO took leadership in what was then called the eradication of leprosy[32] with funds from the United Nations Children's Fund.[33] This new policy also called upon States to amend discriminatory legislation, arguing that such legislation was a barrier to the eradication of leprosy.[34] It was in this period that the first calls emerged from leprosy colonies demanding recognition of the dignity and rights of persons affected by leprosy. It took over a half century to recognize their efforts. However, and in the spirit of the International Conference on Primary Health Care (Alma-Ata, 1978), leprosy was progressively reframed under the right to health.

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[27] International Leprosy Congress, *Memoria del V Congreso Internacional de la Lepra. Celebrado en la Habana, Cuba del 3 al 11 de Abril de 1948. Organizado por el gobierno de la República de Cuba con la colaboración de la Asociación Internacional de la Lepra* (Havana, Editorial Cenit, 1949).

[28] There are still thousands of leprosy colonies throughout the world. Many of those affected still live in these colonies, as well as their children and grandchildren.

[29] Émile Marchoux, *III Conférence Internationale de la Lèpre. Strasbourg, 28 au 31 juillet 1923: communications et débats* (Paris, Baillière et fils, 1924).

[30] Ibid.

[31] G.H. Faget and others, "La prominoterapia de la lepra: estudios en progreso", *International Journal of Leprosy and other Mycobacterial Diseases*, vol. 11, No. 1 (1943), pp. 52–62.

[32] WHO, "Editorial: information and comments on development of international leprosy activities", *WHO Chronicle*, vol. 14, No. 1 (1960), pp. 3–39.

[33] Michel F. Lechat, "The saga of dapsone", in *Multidrug Therapy against Leprosy: Development and Implementation over the Past 25 years*, H. Sansarricq, ed. (Geneva, WHO, 2004), pp. 1–7.

[34] Frans Hemerijckx , "Social aspects of leprosy problem with reference to countries with high leprosy endemicity: epidemiology and control of leprosy", in *Transactions of the VIIth International Congress of Leprology. Tokyo, November 1958. Held Under the Joint Sponsorship of the International Leprosy Association; Tofu Kyokay (Japanese Leprosy Foundation)* (Tokyo, Tofu Kyokai, 1959), pp. 442–447.

Third period of the modern history of leprosy (1981–2010)

39. The third period of the modern history of leprosy began with Sheppard's findings on a technique that allowed for growing *Mycobacterium leprae* in vivo.[35] This technique proved the primary resistance to dapsone. Since primary resistance to dapsone might jeopardize the entire leprosy programme, in 1981, a group of experts from WHO developed a multidrug regime (dapsone and rifampicin — a powerful drug from the field of tuberculosis — for all patients, with clofazimine added for multibacillary patients).

40. From 1986 onwards, great efforts were made to expand the delivery of multidrug therapy. Between 1986 and 1990, the coverage of multidrug therapy saw an increase from 1 to 40 per cent.[36] In 1991, the World Health Assembly adopted resolution WHA44.9 for the elimination of leprosy as a public health problem (defined as a registered prevalence of less than 1 case for every 10,000 persons) in the year 2000. By the end of 2000, the global prevalence of leprosy declined to less than 1 case for every 10,000 persons. In May 2001, WHO announced the global elimination of leprosy as a public health problem.[37] This was a time of great hope, in which the entire leprosy community believed that large-scale delivery of multidrug therapy would not only eliminate leprosy, but also the accompanying stigmatization and discrimination.

41. However, despite such impressive results on the prevalence of leprosy, trends regarding the transmission and detection of new cases did not follow as expected. It became increasingly obvious that leprosy incidence was linked to the social determinants of health, which required more than just a pharmaceuticalized[38] approach. In addition, stigmatization and discrimination hindered people from being diagnosed and treated, as well as from fully enjoying their civil, political, economic, social and cultural rights.

42. As such, during the first decade of the twenty-first century, awareness of the role played by stigmatization and discrimination as barriers to diagnosis and treatment (which had already been pointed out very clearly by leprosy experts as early as 1984 in New Delhi),[39] grew among the key stakeholders. Consequently, this became the decade in which evidence demanded an approach to leprosy as a biosocial phenomenon. The acknowledgement that leprosy remained a medical and social problem in contemporary societies called for an intersectoral approach, which is still to be elaborated and put into practice by leprosy programmes.

43. The first decade of the twenty-first century ended with two historical breakthroughs. First, in 2010, WHO introduced the guidelines for strengthening participation of persons affected by leprosy in leprosy services, acknowledging persons affected by leprosy as powerful agents of change. Second, the General Assembly adopted resolution 65/215 on the elimination of discrimination against persons affected by leprosy and their family members and noted the principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members that had been developed by the Human Rights Council Advisory Committee. This was the founding moment of the global acknowledgement of leprosy as a deep-rooted human rights issue.

44. After the global elimination of leprosy as a public health problem, its status as a neglected and forgotten disease solidified. As such, the beginning of the twenty-first century is characterized by an alarming lack of expertise to diagnose and treat the disease; and reduced funding for basic, clinical and operational research, as well as for tackling both the medical and social dimensions of the disease.

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[35] Lechat, "The saga of dapsone", pp. 1–7.

[36] D. Daumerie, "Implementation of MDT: successive steps", in *Multidrug Therapy against Leprosy: Development and Implementation over the Past 25 years*, H. Sansarricq, ed. (Geneva, WHO, 2004), pp. 45–67.

[37] H. Sansarricq, "The study group", *Multidrug Therapy against Leprosy: Development and Implementation over the Past 25 years*, H. Sansarricq, ed. (Geneva, WHO, 2004), pp. 31–44.

[38] João Biehl, *Will to Live: AIDS Therapies and the Politics of Survival* (Princeton and Oxford, Princeton University Press, 2007).

[39] D.S. Chaudhury, "Global leprosy control: impact of new ideas and priorities", in *XII International Leprosy Congress. Proceedings* (New Delhi, Printaid, 1984), pp. 858–860.

C. Failure of the medicalization of stigmatization and discrimination

Resocializing leprosy-related discrimination

45. The second decade of the twenty-first century was marked by an acknowledgment that the medicalization of stigmatization and discrimination (that is to say, the idea that the availability of medical treatment and the dissemination of medical knowledge about the disease would eliminate stigmatization and discrimination) was not enough to eliminate the historically, socially, politically, economically and culturally entrenched discrimination against persons affected by leprosy. Such discrimination had been systematically reproducing unequal opportunities and access to the goods and services of the State and segregation from community, social and family life, and causing tremendous suffering and distress to persons affected by leprosy.

46. Medicalized interventions on what is narrowly described as health-related stigma are mostly based upon "immodest claims of causality"[40] and not on evidence. They also compartmentalize the problem in a way that fails to grasp its multidimensionality. While the ground-breaking effect of multidrug therapy on the lives of persons affected by leprosy and on the public's image of the disease cannot be dismissed, discrimination persists.

47. Stigmatization and discrimination on the grounds of leprosy must be resocialized,[41] contextualized and approached as interdependent social, economic, political and cultural issues. Stigmatization and discrimination are mutually reinforcing. Enacted stigmatization produces discrimination, which, in return, reinforces stigmatization, trapping persons affected by leprosy in a spiralling chain of disadvantage.

48. It is necessary to analyse how leprosy intersects with other social vulnerabilities. Leprosy-related stigmatization is only the tip of the iceberg[42] of inequalities and inequities that have historically excluded persons affected by leprosy from participating on equal terms in society. Discrimination on the grounds of leprosy is multiple and directly proportional to social vulnerability.

49. However, and despite the current acknowledgment of the persistence of institutionalized and structural discrimination against persons affected by leprosy and their family members, existing indicators used to assess discrimination are mostly based on the medical model. It is crucial to develop new tools that, in the light of the progress achieved by the social model of disability, may be able to identify how societies erect barriers to the full inclusion of persons affected by leprosy and how those same barriers can be taken down.

50. Discrimination on the grounds of leprosy is institutionalized, public, iatrogenic, affiliated, multilayered and must be understood in its social, economic, political and cultural context. In order to respond to discrimination in an effective way, it is necessary to identify the societal spheres in which it occurs and manifests itself. Discrimination on the grounds of leprosy may be found at the: (a) macrolevel of the State (in laws, jurisprudence and public policies); (b) intermediary level of State goods and services, such as health services, education, work opportunities and regulation; and (c) microlevel of community life and/or the family.

Institutionalized and structural discrimination

51. Legal dogmatics alone has failed to acknowledge the gap between written law and the practice of law. Discriminatory laws and policies are not the only reason for the exclusion of persons affected by leprosy, but also the lack of effective implementation of

[40] A. Castro and P. Farmer, "Understanding and addressing AIDS-related stigma: from anthropological theory to clinical practice in Haiti", *American Journal of Public Health*, vol. 95, No. 1 (2005), pp. 53–59.

[41] Richard Parker and Peter Aggleton, "HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action", *Social Science and Medicine*, vol. 57, No. 1 (2003), pp. 13–24.

[42] Castro and Farmer, "Understanding and addressing AIDS-related stigma", pp. 53–59.

the already recognized rights, such as access to the highest attainable standard of health, education and justice. Access to the enjoyment of rights depends on extra-institutional factors, such as educational level, inclusion or exclusion from the formal labour market, gender inequalities and racial discrimination. Given the generalized vulnerability of persons affected by leprosy, the gap between written law and the practice of law is severely exacerbated.

52. Laws that discriminate against persons affected by leprosy still exist in many parts of the world. These laws disregard and disrespect international human rights standards, in particular the principle of non-discrimination as stipulated in the Universal Declaration of Human Rights, the International Covenants and subsequent human rights instruments.

53. In 2016, nine countries reported to WHO the existence of discriminatory laws against persons affected by leprosy.[43] A survey conducted by the International Federation of Anti-Leprosy Associations identified more than 20 countries with discriminatory laws, covering segregation, immigration, marriage, voting, public transportation, employment and housing, and violating civic, political, economic, social and cultural rights. According to the survey, 50 per cent of those laws identified as discriminatory are still active and/or with an unknown status and only 8 per cent are under review. Some 52 per cent of those laws were found in the Asian region, followed by 8 per cent in Europe and North America, 7 per cent in Africa and 2 per cent in Oceania. Such laws concern: segregation and separation (29 per cent); immigration (16 per cent); marriage and divorce (10 per cent); employment and voting (6 per cent); public transportation (5 per cent); and residence (2 per cent). Many of these laws date back to the late nineteenth century and early twentieth century, but some are as recent as the late twentieth century and first decade of the twenty-first century.[44]

54. The drafting group in its progress report submitted to the Advisory Committee on the implementation of the principles and guidelines on the elimination of discrimination against persons affected by leprosy and their family members[45] also made an effort to map discriminatory laws and practices in order to assess the implementation of the principles and guidelines in different countries. The report is, however, built upon a major gap regarding information from endemic countries, since the majority of the responses were from States in which leprosy was not a major issue. The drafting group acknowledges that discriminatory laws and policies still exist in many countries, depriving persons affected by leprosy from fundamental civil and political rights. It also argues in favour of a more thorough review of the aforementioned laws and policies in order to make positive changes. It goes on to say that such problems are probably not restricted to leprosy-endemic countries, but might also be found in countries in which leprosy was considered a disease of the past. The drafting group identifies discriminatory practices that hinder the enjoyment of the economic, social and cultural rights of persons affected by leprosy, such as divorce on the grounds of leprosy with a strong gender bias or denial of access to school and education to children affected by leprosy, among others. Finally, the drafting group determines that national plans to implement the principles and guidelines are still to be developed; the current level of implementation remains unsatisfactory.

55. In addition to law, jurisprudence and public policies, discrimination is also a reality in the administration of certain States, particularly in health services, education and State benefits, reaching extra-institutional settings, such as the workplace, marriage and community and family life. Discrimination against persons affected by leprosy is so pervasive that it even materializes in exclusionary interpersonal relations that impose the separation of food, spaces and household and work-related objects, and that exclude touching persons affected by leprosy, which is one of the most basic human senses employed in socialization and mutual acknowledgment. This multilayered discrimination

[43] WHO, *Weekly Epidemiological Record*.

[44] See https://www.ilepfederation.org/wp-content/uploads/2017/03/Table-discriminatory-laws-2March2017.pdf.

[45] Available from www.ohchr.org/EN/HRBodies/HRC/AdvisoryCommittee/Pages/Leprosy.aspx.

often causes severe depression, resulting in a high incidence of self-isolation and self-exclusion, as well as mental illness.[46]

56. Not only are persons affected by leprosy stigmatized and discriminated against, their families are equally affected by courtesy stigma. Even though courtesy stigma may also affect caregivers,[47] it is the family members of persons affected by leprosy that bear the brunt of the worst of discrimination. In many social and cultural contexts, entire families are discriminated against and stigmatization and discrimination may have an impact for two or even three generations.

IV. Structuring the mandate

A. Background

57. In 2010, the General Assembly, in a landmark move, adopted resolution 65/215 and took note of the principles and guidelines on the elimination of discrimination against persons affected by leprosy and their family members. In so doing, it established leprosy as a human rights issue and stressed that persons affected by leprosy and their family members should be treated as individuals with dignity and entitled to all human rights and fundamental freedoms under customary international law, the relevant conventions and national constitutions and laws.

58. The resolution and the principles and guidelines were preceded by resolutions 8/13 and 12/7 of the Human Rights Council, from which a report and a draft set of principles and guidelines resulted. In resolution 15/10, the Council took note with appreciation of the set of principles and guidelines and invited the General Assembly to consider, as appropriate, the issue of the elimination of discrimination against persons affected by leprosy and their family members, including possible ways to promote further the principles and guidelines.

59. In June 2015, the Council adopted resolution 29/5, mandating the Advisory Committee to undertake a study to review the implementation of the principles and guidelines and to submit a report containing practical recommendations for the wider dissemination and more effective implementation of the principles and guidelines.

60. While the progress report had failed to properly assess the implementation of the principles and guidelines in endemic States, it recommended, however, the establishment of a follow-up mechanism within the United Nations system to monitor and report on progress, and to encourage States and other relevant actors to bring their conduct into line with what was provided in the principles and guidelines.

61. In June 2017, the Council adopted resolution 35/9, establishing the mandate of the Special Rapporteur on the elimination of discrimination against persons affected by leprosy and their family members. It called on States and all relevant stakeholders to cooperate with the Special Rapporteur in the discharge of the mandate. It also requested the Secretary-General and the United Nations High Commissioner for Human Rights to provide the means for the effective fulfilment of the mandate. Finally, it encouraged the High Commissioner and the Special Rapporteur, in collaboration with States and the relevant international organizations, as well as non-governmental organizations, to organize seminars on leprosy-related discrimination in order to widely disseminate the principles and guidelines, also ensuring substantial participation of persons affected by leprosy.

[46] See https://www.ilepfederation.org/news-item/why-we-must-talk-about-leprosy-stigma-and-mental-health/.

[47] M. Dako-Gyeke, "Courtesy stigma: a concealed consternation among caregivers of people affected by leprosy", *Social Science and Medicine* (January 2018), pp. 190–196.

B. Mandate

62. The Council decided to appoint the Special Rapporteur for a period of three years with the following mandate:

(a) To follow up and report on progress made and measures taken by States for the effective implementation of the principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members for the realization of the enjoyment of human rights by persons affected by leprosy and their family members in all regions of the world, and to make recommendations to the Council in this regard;

(b) To engage in dialogue and consult with States and other relevant stakeholders, including United Nations bodies, specialized agencies, funds and programmes, in particular WHO, other intergovernmental, regional human rights mechanisms, national human rights institutions and non-governmental organizations to identify, exchange and promote good practices relating to the realization of the rights of persons affected by leprosy and their family members, and to their participation as equal members of society with a view to achieving a leprosy-free world;

(c) To raise awareness of the rights of persons affected by leprosy and their family members and to combat stigmas, prejudices and harmful traditional practices and beliefs that hinder their enjoyment of human rights and fundamental freedoms and their participation in society on an equal basis with others;

(d) To report annually to the Council, starting from its thirty-eighth session.

63. The Special Rapporteur commends the establishment of the mandate as an important milestone in addressing the marginalized and mostly forgotten segment of population that experience multiple discrimination and violation. As a new mandate within the Council, the Special Rapporteur will identify key areas in which she can effectively contribute to the advancement of the rights of persons affected by leprosy and their family members. For the effective implementation of the duties and responsibilities assigned to the mandate, the Special Rapporteur should rely on the support of the States, partners and other stakeholders, especially civil society and organizations of persons affected by leprosy.

C. Vision

Intersectionality and affirmative action

64. Leprosy-related discrimination is multiple and multilayered and there is sufficient evidence to suggest that leprosy commonly intersects with other identity labels subjected to oppression, marginalization, exclusion and violence. Among the more frequent social conditions and identities that intersect with leprosy are: gender; ethnicity and/or race; age; disability; migration; and poverty.

65. In fact, intersectionality is key to an in-depth understanding of leprosy-related discrimination. Intersectionality as a concept came from feminist theory and politics. Its origin came from the need to understand the discrimination of black women through an analysis that simultaneously encompassed gender and race. Intersectionality is not an additive approach. Accordingly, different categories do not accumulate, but interrelate in dynamic ways that always have a particular system of domination as a background.[48] This means that intersectionality stands for the numerous effects that result from the intersection of distinct differential axes in specific historical contexts. It also states that different dimensions of social life cannot be artificially separated into pure phenomena.[49] In practice,

[48] Patricia Hill Collins, *Black Feminist Thought: Knowledge, Consciousness, and the Politics of Empowerment* (Boston, Unwin Hyman, 1990).

[49] Avtar Brah and Ann Phoenix, "Ain't I a woman? Revisiting intersectionality", *Journal of International Women's Studies*, vol. 5, No. 3 (2004), pp. 75–86.

this means that leprosy-related discrimination affects in different ways a person according to his or her social status and capital.

66. Tackling leprosy-related discrimination based on an approach that acknowledges the intersection of leprosy with other social phenomena of oppression and violence does not mean blurring leprosy into the wider picture of social inequities, inequalities and injustice. On the contrary, that would only increase discrimination and strengthen the structural violence experienced by persons affected by leprosy and their family members by contributing to their invisibility.

67. Tackling leprosy-related discrimination on the basis of an approach that acknowledges the intersection of leprosy with other social phenomena of oppression and violence means producing in-depth analysis and knowledge, contextualizing interpretations on social and cultural milieus and developing more accurate and effective tools. Intersectionality is key for analysis, but responses for action must come from other tools.

68. Given the multiple and multilayered discrimination against persons affected by leprosy and their family members, one of the more important tools to be developed and improved is affirmative action, in order to balance the terms that establish not only opportunities, but also outcomes, for persons affected by leprosy.

69. In fact, formal equality in law can result in increasing inequalities, marginalization and invisibility when it fails to recognize the different conditions that specific groups experience and struggle with. From the acknowledgement of such differences, the concept of material equality was born, which aims at a substantive analysis of social realities and practices that goes beyond legal dogmatics or a formal analysis of legal equality.[50]

70. One of the several tools able to generate material equality is affirmative action, which means creating mechanisms or policies that allow for protecting and supporting specific social groups that dwell in structural disadvantage, thus enabling equality of opportunities and/or outcomes and eliminating the barriers to the achievement of real and effective equality.[51] Measures of affirmative action can take many forms and their use, characteristics and goals for addressing the structural discrimination of persons affected by leprosy and their family members must also be dependent on the context of implementation.

Vulnerability and intersectorality

71. As detailed in previous chapters, leprosy is not a residue from the past. On the contrary, leprosy is a contemporary disease closely linked with structural vulnerability. The impact of leprosy on the lives of persons affected is still severe and depends on the capacity of States to ensure: (a) functional, and culturally and gender-sensitive access to health services; (b) early diagnosis; (c) high-quality medical care during treatment and after; and (d) social policies that fit the specific needs of persons affected by leprosy (regarding gender, education, housing, work and disability, among others) and access to them. This means that the impact of leprosy on the lives of persons affected is proportional to their vulnerability and resilience.

72. The concept of vulnerability refers to the diminished capacity of an individual or group to anticipate, cope with, resist and recover from any hazard. People differ in their exposure to hazard and leprosy-related discrimination is undoubtedly a factor that increases vulnerability. However, vulnerability also increases the impact of leprosy on the lives of persons affected.

73. Vulnerability must be understood as a political, economic, social and cultural condition and not as an ontological feature of a group of persons. That is to say, any

[50] Roxana Arroyo Vargas, "Igualdad un largo camino para las mujeres", in *Igualdad y no discriminación, el reto de la diversidad*, Danilo Caicedo Tapia and Angélica Porras Velasco, eds. (Quito, Ministry of Justice, Human Rights and Religious Affairs, 2010), pp. 421–447.

[51] Judith Salgado Álvarez, "Lidiando con la diferencia. Respuestas desde la justicia constitucional ecuatoriana y colombiana", in *Igualdad y no discriminación, el reto de la diversidad*, Danilo Caicedo Tapia and Angélica Porras Velasco (Quito, Ministry of Justice, Human Rights and Religious Affairs, 2010), pp. 483–546.

analysis of vulnerability must distinguish between the conditions that diminish an individual's or a group's capacity to cope with hazard, from the multiple and creative ways that individuals and groups usually develop to resist it, despite their very limited options and resources.

74. Persons may live in conditions of vulnerability, but they themselves should not be considered as lacking agency in facing those same conditions. In fact, policies for tackling vulnerability should take into consideration the ways through which individuals and groups face vulnerability.

75. Having said this, and reaffirming that the impact of leprosy and leprosy-related discrimination is proportional to the degree of vulnerability experienced by persons affected, it is mandatory to develop tools to assess vulnerability and the means to tackle it.

76. One important tool is the framework provided by the Sustainable Development Goals. Such a framework may be of great help in developing an intersectoral governance that might avoid duplicity of actions, as well as enhance efficiency, effectiveness and efficacy. In fact, many of the areas of action outlined by the Goals are key in tackling leprosy-related vulnerability and discrimination, such as poverty, hunger, good health and well-being, education, gender, clean water and sanitation, decent work and economic growth, reduced inequalities, and sustainable cities and communities.

77. Intersectorality is key in decreasing vulnerability to leprosy and leprosy-related discrimination. Moreover, in order to strengthen the intersectoral approach, the implementation of the principles and guidelines should be allied with the 2030 Agenda for Sustainable Development.

78. Historically, leprosy became a symbol for exclusion. Recognition by the United Nations of leprosy as a human rights issue has, however, closed that dark chapter of history. Such recognition will advocate for inclusiveness and participation. Being a cross-cutting issue, leprosy can be used as a model for the accomplishment of sustainable development and as a symbol of the reinforcement of human rights. Notably, the international community, civil society and other relevant stakeholders have obligations to keep individuals affected by leprosy and their family members high on the 2030 Agenda. If, by 2030, persons affected by leprosy and their family members have not been left behind, the long-standing issues of social exclusion and invisibility that affect a substantive segment of the population will have been addressed.

Participation and lay expertise

79. Participation is key for the long-term elimination of leprosy-related discrimination and for a sustainable inclusion of the affected persons and their family members.

80. Participation is multidimensional and includes the elements of representative democracy (the right to vote, to be elected and to hold public office), participatory democracy (elaboration, execution, monitoring and accountability in policymaking), non-governmental organizations and communities (decision-making) and epistemic communities (participation in the production of knowledge), among others.

81. Participation is thus not restricted to the macrospace of the State. It is also interrelated with all human rights, since it is not possible to participate in society at large without enjoying the rights to freedom, work, health, education, a dignified life, freedom of expression and information, among others. Without the fulfilment of human rights, participation becomes a mere formality. In turn, without participation, human rights becomes questionable.

82. For the present purposes, participation is understood as: (a) equal opportunities to participate and enjoy civil, political, economic, social and cultural rights and, when applicable, collective rights;[52] (b) the right to participate in all decision-making processes that might have an impact on the lives of persons affected by leprosy and their family

[52] For instance, the right to memory is liable to be treated as a collective right of persons affected by leprosy, who were forcibly segregated from their families, communities and society.

members (such as scientific research, public health programmes, health services, policymaking and collective organization); and (c) the right to participate in the elaboration, monitoring, evaluation and accountability mechanisms of public policies that might have an impact on the lives of persons affected by leprosy and their family members.

83. Participation in decision-making is not only a right, it is also pivotal for the production of more effective responses to problems. Persons affected by leprosy develop situated knowledge that differs from the knowledge produced by science or the State. Unlike science or State management, lay knowledge does not separate life into different spheres. Instead, it is able to create a synthesis between history, society, culture, etiology and disease. As such, it is particularly helpful in producing new and much needed geographies that might map the complex intersection between leprosy and social factors. By being close to communities, leprosy organizations also know first-hand the difficulties and needs of the persons affected, which are often invisible in State surveys. They are, as such, experts on health and equality data. Such situated knowledge generates alternative evidence, as demonstrated by popular epidemiology. Situated knowledge is also key to evaluation and accountability. Finally, the lay knowledge of organizations of persons affected by leprosy should be taken into consideration for the design of scientific research and policymaking.

84. Participation also means the right to an active voice in public life. Therefore, the strengthening of organizations of persons affected by leprosy is crucial in enabling such persons and their family members to be their own representatives in public spaces. The organizations also promote a positive identity among persons affected by leprosy. With a positive identity, people start making changes to their surroundings and they tend to make them in an effective way. That is a major contribution towards rights and dignity awareness, as well as towards changing public perceptions of the disease. Finally, such participation in public life is key in achieving the structural change in which the automatic social response of rejection gives way to an empathic understanding of similarities, that is to the recognition of equality. That is why affirmative action and intersectoral governance should create conditions in which persons affected by leprosy can be empowered in such a way as to become the leading protagonists in the elimination of leprosy-related stigmatization and discrimination and ensure its sustainability in the long term.

D. Methodology

85. In the discharge of the mandate, the following methodology will be central to the Special Rapporteur's work.

Principles

86. Civic engagement: the Special Rapporteur will engage and hold regular dialogue with States, United Nations agencies, funds and programmes, civil society organizations and other relevant partners, including persons affected by leprosy and their family members and their representative organizations.

87. Participation: openness, consultation and participation will remain the driving principles of the Special Rapporteur's working methods and will actively involve local actors, civil society activists and organizations of persons affected by leprosy in her work.

88. Inclusiveness: the Special Rapporteur will work in an inclusive manner and will pay attention to groups that are more vulnerable to leprosy-related discrimination, in particular women, children and persons affected by leprosy-related disabilities.

Methods of work

89. Annual reports: as mandated by resolution 35/9, the Special Rapporteur will submit annual reports to the Human Rights Council on the activities undertaken in the fulfilment of her mandate and thematic issues.

90. Country visits: at the invitation of Governments, the Special Rapporteur will make country visits and engage with the country concerned on the implementation of the

principles and guidelines, identification of good practices and the provision of technical advice on policymaking and capacity-building.

91. Communication: the Special Rapporteur will gather, request and exchange information with relevant stakeholders, including States.

92. Identification and dissemination of good practices: the Special Rapporteur will consult States and other stakeholders on the identification and promotion of good practices in the elimination of stigmatization and discrimination against persons affected by leprosy and their family members and on guaranteeing their fundamental rights and inclusion.

93. Building cooperation: the Special Rapporteur acknowledges the crucial role played by the United Nations human rights treaty bodies, the special procedure mandate holders and the universal periodic review in the promotion of human rights globally and will build cooperation to give visibility to leprosy in their work. The Special Rapporteur will work with relevant actors and stakeholders to promote awareness-raising on the rights of persons affected by leprosy and their family members and combat stigmatization, prejudice and harmful practices and beliefs that hinder their enjoyment of human rights and fundamental freedoms.

E. Human rights instruments and standards

Principles and guidelines for the elimination of discrimination against persons affected by leprosy and their family members

94. In its resolution 35/9, the Human Rights Council mandated the Special Rapporteur to monitor the effective implementation of the principles and guidelines, which recognize the fundamental human rights of persons affected by leprosy and their family members. The principles and guidelines encourage States to promote, protect and ensure the full realization of all human rights of persons affected by leprosy and their family members.

95. Although the principles and guidelines are not legally binding, they are, however, in line with the human rights standards and reinforce the principle of non-discrimination as a core element stipulated in the Universal Declaration of Human Rights and other human rights instruments. The principles and guidelines provide measures for calling States to account on their duty and responsibility to prohibit discrimination against persons affected by leprosy and their family members, as well as to protect, promote and ensure their human rights. Additionally, the content of the principles and guidelines takes its spirit from the provisions of the human rights treaties.

96. Given the cross-cutting nature of leprosy, the work of the Special Rapporteur will be guided by the relevant conventions, especially: the International Covenant on Economic, Social and Cultural Rights; the International Convention on the Elimination of All Forms of Racial Discrimination; the Convention on the Elimination of All Forms of Discrimination against Women; the Convention on the Rights of the Child; the Convention on the Rights of Persons with Disabilities; and the International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families.

97. Finally, the Special Rapporteur will promote the use of the principles and guidelines among the stakeholders and persons affected by leprosy and their family members as a rights-dissemination instrument, empowerment strategy, and evaluation and research tool.

Monitoring implementation of the principles and guidelines at the national level and States' efforts to ensure non-discrimination and full inclusion

98. The monitoring of the implementation of the principles and guidelines and of States' efforts to ensure non-discrimination and enforce the human rights of persons affected by leprosy and their family members will be sensitive to the epidemiological diversity of leprosy worldwide. Priority will be given to endemic countries and will take into consideration the following:

(a) Regional accountability mechanisms — jurisprudence from existing regional human rights systems of protection,[53] the recommendations produced by them and the extent of their implementation;

(b) National legislative frameworks, public policies and participation mechanisms — to evaluate how States should advance towards the prohibition of discrimination on the grounds of leprosy and towards the protection, promotion and enforcement of the human rights of persons affected by leprosy and their family members, the following will be assessed:

(i) Measures taken to ensure, at the normative, jurisdictional and policymaking levels, the rights of persons affected by leprosy and their family members as established by the principles and guidelines, as well as measures taken to ensure access to them;

(ii) Measures taken for raising awareness about leprosy;

(iii) Measures taken to ensure the participation of persons affected by leprosy in decision-making processes concerning issues related to them and in following up States' activities to implement the principles and guidelines.

99. Additionally, the following will also be assessed to enable the identification of good practices and formulate pragmatic and realistic recommendations on implementing the principles and guidelines:

(a) How domestic constitutional law coordinates and integrates States' commitments under international human rights law;

(b) The state of national anti-discriminatory laws, public policies related to the realization of economic and social rights and the existence of judicial and administrative remedies available to enforce human rights and monitor public policies, and of public participation mechanisms;

(c) National justice systems, or how domestic courts have adjudicated in cases related to the rights and freedoms of people affected by leprosy and their family members and also heard cases related to discrimination laws and economic, social and cultural rights implementation, in order to develop a better understanding about the use of courts and national case law as an accountability mechanism.

F. Priorities for the mandate

100. Given the limited availability of resources, the Special Rapporteur has identified two priority areas that she deemed key in the promotion of the rights and freedoms of persons affected by leprosy and their family members. These priorities resulted from a consultation undertaken by the Special Rapporteur with some of the main stakeholders in the field of leprosy,[54] as well as national NGOs and organizations of persons affected by leprosy,[55] which allowed persons affected by leprosy and their family members to be consulted in more than 40 countries. These consultations were aimed at developing a framework that gives primacy to the following priorities:

(a) Enforcement of equality — harmonize domestic laws and practices with international law, as well as guarantee effective access to rights, in order to tackle the

[53] African Commission on Human and Peoples' Rights, the Inter-American Commission on Human Rights and the Inter-American Court of Human Rights.

[54] Among them: the International Federation of Anti-Leprosy Associations, the Nippon Foundation, Sasakawa Memorial Health Foundation, Leprosy Mission International, the International Association for Integration, Dignity and Economic Advancement, the International Leprosy Association, WHO and the Pan American Health Organization.

[55] For example: Movimento de Reintegração de Pessoas Atingidas pela Hanseníase, Perhimpunan Mandiri Kusta, the Coalition of Leprosy Advocates of the Philippines, Handa Rehabilitation and Welfare Association and Felchansen.

structural disadvantage of persons affected by leprosy and their family members and empower them;

(b) Acknowledgement of equality — eliminate stigmatization and prejudice through strengthened awareness-raising, and promote change in the social perception of persons affected by leprosy and their family members by encouraging their public participation and by disseminating guidelines for the generic use of images, language and contents.

V. Conclusions

101. **The Special Rapporteur regards the establishment of the mandate as a historical breakthrough that provides a great opportunity to address the widespread, institutionalized and structural discrimination against persons affected by leprosy and their family members. The Special Rapporteur considers this breakthrough as evidence of the United Nations human rights system's commitment to the realization of leaving no one behind — a goal stressed in the 2030 Agenda for Sustainable Development.**

102. **During the discharge of her duties and in accordance with the mandate entrusted to the Special Rapporteur by the Human Rights Council in its resolution 35/9, she will pay particular attention to the groups that live in more vulnerable conditions to leprosy-related discrimination, giving due consideration to the diversified national and local realities.**

103. **The Special Rapporteur aims to undertake the mission entrusted to her in a collaborative manner, working closely with States, the United Nations system — in particular, its human rights mechanisms — intergovernmental agencies, academics and the main stakeholders in the field of leprosy, civil society organizations and organizations of persons affected by leprosy. The Special Rapporteur sees consultation and dialogue as a crucial part of her mandate and will offer, as appropriate, technical advice, especially in the area of capacity-building, which is key for the elimination of leprosy-related discrimination.**

104. **Given the demanding nature of the mandate and the expectations of persons affected by leprosy and their family members, the Special Rapporteur appeals to States, the United Nations system, regional entities and the main stakeholders to join her in her efforts to bring the needed change to the lives of persons affected by leprosy and their family members and ensure that leprosy becomes a positive symbol of inclusiveness in the 2030 Agenda.**